

INFANT DEVELOPMENT PROGRAMMES: CONSUMER SATISFACTION IN THE GAZA STRIP

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Attempts to measure the effectiveness of human service programmes have inherent problems concerning the subjectivity and objectivity of the data on which the evaluations are based. Usually social scientists prefer objective measures which show that subjects have increased their performance on one variable or another. However objective performance measures are not the only ones against which programme success must be measured.

Brown (1987, 1988) writes of attempting to assess the quality of life of mentally handicapped adults using both subjective and objective measures. On many occasions he and his colleagues (Brown et al., 1988) found discrepancies in their evaluations. For example, a young woman with severe cerebral palsy living with her wheelchair-bound and terminally-ill husband in a small, sparsely furnished apartment reported many positive feelings about the quality of her life. While her subjective opinion is very important, so is the objective data concerning her situation. Brown sensibly summarises the "state of the art" in measuring quality of life by saying that at this point in time we must attempt to synthesise both subjective and objective data in order to evaluate the effectiveness of programmes.

The Society for the Care of the Handicapped in Gaza has a reputation in the Developing World as a pioneer of excellence in the provision of early intervention programmes for handicapped infants. In the last five years, visiting consultants and foreign funding agencies have written a number of very positive reports on the effectiveness of the Mothers Home Education Programme, e.g. Affi et al. (1988). Nevertheless, the Society continues to pursue excellence in service delivery and to this end has embarked upon an ambitious and rigorously-objective evaluation of this programme (Oakland & Abu Ghazaleh, in preparation).

In contrast to the more-objective approach, the present paper seeks to measure subjective satisfaction among consumers of the Mothers Home Education Programme. Our position is that in order to be considered successful, a programme must have not only a demonstrably positive effect but must also improve the consumers' subjective evaluation of the quality of their lives.

METHOD

The Mothers Home Education Programme was established in 1984 with the goal of giving home-based education to the mothers of handicapped children aged from birth to eight years in order to help them to maximise their children's cognitive development. At present 35 teachers visit 700 families on a weekly basis,

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providing the mothers and children with developmental goals, instruction, education materials and emotional support, as well as systematically evaluating progress. Services are provided in all parts of the Gaza Strip including towns, villages, refugee camps, and rural areas.

In partnership with the University of Calgary and Mount Royal College, the Society for the Care of the Handicapped also offers college and university-level teacher training programmes to young Palestinian adults through the Sun Centre in Gaza. The skills of one such group of students were utilised in the present study. After successfully completing courses in counselling skills and programme management, the students assisted in the preparation of a consumer satisfaction questionnaire for the Mothers Home Education Programme and then proceeded to administer it in the homes.

The study was developed and implemented as follows:-

1. The authors met with 18 students and discussed the titles of the main sections of the questionnaire.
2. These were:-
 - A. Demographic Information
 - B. Historical Background of Child
 - C. Knowledge of the Programme
 - D. Parents Relationship with Teacher
 - E. Barriers to Service
 - F. Recommendations
3. The students worked in small groups each of which had the task of creating a list of questions suitable for one of the sections.
4. Following discussions with the whole class, questions deemed appropriate were selected from the lists provided by the student groups. Informational and cultural factors were found to be the most important in the selection or rejection of specific questions.
5. The questionnaire was first written in English and then translated into Arabic by the junior author who holds a baccalaureate degree in Arabic Language.
6. Next 36 families were randomly selected from those who are registered with the programme. They were informed of the study and invited to participate. Due to local conditions, it proved impossible to contact two families and they were replaced by other random selections from the list.
7. All responses from the families appeared to be positive and on two successive Saturdays, pairs of students visited the families and conducted the interviews. Saturday was selected as it is the day when many Palestinian men are home from their jobs in Israel and therefore it is easier for young male students to enter the houses.
8. During each interview, one student asked the questions while the other recorded the answers. As each pair conducted two interviews, the students had the opportunity to be both the interviewer and recorder. Each interview lasted

from one to one and a half hours, thus giving the students opportunity to develop some feelings of trust with the respondents and to pursue some of the questions in depth.

In all 34 families were interviewed. Two were not at home when the students called.

RESULTS

Demographic Information:

The families of 17 male and 17 female children were interviewed. The mean age of the children was 7.5 years with a range from 3 to 9. The primary diagnosis of 18 children was a speech or hearing problem. Mental retardation was the primary diagnosis of 5 others, while the rest suffered from a variety of mental and physical handicaps. In 12 of the 34 nuclear families, there was more than one handicapped child.

The mean age of the fathers was 37 years with a range from 22 to 65. In terms of their occupations, 18 were casual labourers in Israel, i.e. the primary occupation of adult males in Gaza. Of the others, 9 were employed as semi-skilled workers such as electricians and drivers, while 3 more had professional training in education and law. Four were listed as being unemployed.

Twenty of these men were married to their first cousins, and a further 11 had a wife who was a more distant relative. Only 3 had married outside their extended family.

Mothers ranged in age from 21 to 50 years, with a mean of 34. None of them worked outside the home. The average age of the mother at the time of the birth of the handicapped child was 26.76 years with a range from 15 to 40.

As would be expected in an Islamic culture, families tended to be large. The largest family had 12 children and the smallest 2, while the mean was 7. The position of the handicapped child ranged from first to eleventh with a mean of 4.9. In addition, due to members of the extended family often living together, between 3 and 20 people were residing in one home. The average was about 10 persons.

Historical Background of the Child:

Most children, i.e. 18, were first admitted to the programme between the ages of 2 and 4 years. Nine others were admitted between the ages of 5 and 7 years, while 7 more were less than 2 years old when first seen by the home teacher. Half of the children began to receive services within one month of an application being made to the programme. Everybody was served within 4 months.

More than three quarters of the parents learned about the Mothers Home Education Programme from their friends, neighbours and relatives. Only three families were referred by a medical practitioner.

At the time of the interviews, the children had been in the programme for a period of a few months to 5 years with a mean of 2.88 years. During this time from 1 to 8 teachers had come to their homes, indicating that each family had received an average of 3.26 teachers. Although individual teachers had stayed

with individual families anywhere from 6 months to 3 years, the mean length of the relationships was 12.35 months. As ongoing relationships are included in the data, these should be considered somewhat conservative figures.

Consumers' Knowledge of the Programme:

In general terms, the families had some accurate information about the programme. For example, 27 of 34 knew the name of the programme and 26 of them knew that it serves about 500 families. In addition 27 of 34 correctly identified the name of the current teacher of their child.

Mixed responses were obtained on a variety of items. Less than half of the families knew which organisation operates the programme and 19 of 34 knew who provides the funding. Less than half could name the director of the project and a corresponding number were unable to name the supervisor of their child's teacher.

In some areas there was a distinct lack of knowledge. Five families were able to correctly identify the purpose of the programme and 9 said they would know who to contact if they were having a problem with the child's teacher. 22 families did not know of any other services offered by the Society for the Care of the Handicapped in Gaza.

Due to the nature of the programme, parents did not regularly visit the programmes administrative offices. 27 respondents had visited the centre, and 7 had attended on more than 3 occasions. In most cases, access was via taxi. Thirteen families were able to give the location of the administrative offices and 15 had the telephone number of the Mothers Home Education Programme.

Parents' Relationships with Teachers:

Responses in this area were overwhelmingly positive. Every family rated their relationship with the teacher as "Very Good" or "Excellent". Thirty two families had not experienced any problems with the teachers and a similar number indicated that the home teacher appreciated that the mother had many important things to do in the home in addition to teaching her handicapped child. Furthermore, everybody said that the teacher always arrived for her scheduled appointments, and all but one family said she arrived punctually, at a convenient time and dressed appropriately.

Teacher's Relationship with Child and Family:

Throughout the interviews the parents reported being very happy about the interactions between their families and staff people from the programme. For example, everybody said that the teacher treated the child and the family in a positive way. Thirty three of 34 rated the relationship between the teacher and child as "Very Good" or "Excellent", while 25 rated the relationship between the teacher and other family members in a similar way. "Average" was the lowest rating obtained on any of these questions.

The families were asked about children's feelings on seeing the teacher enter the home. Most handicapped children were happy when the teacher came, but there were also occasional reports of feelings of sadness, fear and embarrassment.

Other children in the families were also happy to see the teacher, but in 13 homes the siblings were also reported as being a little jealous. It was also noted that in many families, the brothers and sisters helped the teacher to work with the handicapped child.

Results of the Intervention:

Generally, parents felt positive about the progress made by their child. For example, 33 said the child had made progress since entering the programme and 32 rated the teacher's competence as "Very Good" or "Excellent". It was also reported that some 30 children also thought they were improving due to their involvement in the project. Furthermore, 30 parents commented that they had the opportunity to make suggestions about their child's individualised educational plan.

When asked to identify the domains in which the child had made the most progress, 6 areas were identified. These were communication, self-help, motor skills, cognition, social responses, and academics. It is interesting to note that these areas were also mentioned as the areas in which the children had made the least progress!

Criticisms tended to focus on the need for more programming of this kind. Eleven families complained that their child did not get enough treatment or that the sessions were too short, while others were concerned that lessons were missed due to the frequent curfews imposed by the military authorities and the strike days called by the local leadership of the popular uprising. Furthermore, a major concern was that the programme is terminated when children reach the age of 8 years and there are few other resources for handicapped youngsters in the Gaza Strip.

Barriers to Service:

Questions in this section were designed to assess the acceptance of the programme by the general community, and any possible stigmatisation associated with a van from the Society for the Care of the Handicapped arriving at the home on a regular basis. While 4 of the families felt a negative emotion on seeing the bus coming to their home, the rest felt either "neutral" or "happy". Moreover, 30 families thought that their neighbours reacted positively to the sight of the van and the knowledge that their handicapped child was receiving help from the Society.

Recommendations:

About two-thirds of the families made recommendations which they thought would improve the education of their child. The most frequent of these were for more schools for handicapped children and also for vocational training programmes where handicapped youth could learn some marketable job skills. The parents of children with hearing impairments also decried the paucity of specialised services for their children. Less-frequently voiced recommendations in relation to the existing programme were for speech therapy, more academic skills training, and longer lessons.

DISCUSSION

The families interviewed appear to be representative of the present living situation in Gaza. The majority of the men work as unskilled labourers in Israel or have semi-skilled employment within the area under military occupation. The women are all homemakers and do not work in the community. Family groupings are large with up to 20 members living under the same roof.

Some of the findings of previous studies are replicated, while others are not. For example, the large number of marriages between relatives suggests that this may have been a casual factor in the origin of the children's handicaps. In contrast these children appear not to have been born to older mothers, although this finding may have been confounded by the factor of intermarriage.

However, the most important finding of this study may be the parents' strong feelings of satisfaction with the programme, combined with the beneficial aspects of its reputation in the community. Not only are families hearing about the programme from their friends and neighbours, they are enhancing its reputation by continuing to comment on the benefits their children are receiving. Furthermore they seem to dread the day when their children will become too old for this type of education and resent the scarcity of follow-up services. It seems that such reactions are in no small measure due to the supportive and ongoing presence of the teachers in their homes.

These subjective evaluations of early intervention programmes are seldom supported by the more objective studies which have been completed to this point (Kysela and McDonald, 1989). It seems that the factors valued by the parents are not those which have been objectively measured by researchers. For example, Johnson (1987) observed that home teachers in Canada formed a vital link between the mother and the community by filling many roles including those of chauffeur, counsellor and confidante. It is suggested that in accord with Social Action Theory, the success of the Mothers Home Education Programme is due to the support provided to the parents rather than to the amelioration of the children's handicapping conditions.

If one accepts that this type of education is valuable, the age at which children are admitted to the programme gives rise to some concern. For example, almost a quarter of the present group did not begin to receive services until after they had reached the age of five years. However this does not seem to be due to the response time of the programme which appears to have the enviable record of being able to provide service to all children within four months of receiving their applications. Consequently, it is suggested that further community education is needed in order to encourage parents to present their at-risk children for assessment at the earliest opportunity.

In addition, it would be useful if parents knew more about the overall programme. For example, everybody should know the names and telephone numbers of (a) their child's teacher, (b) the director of the programme, and (c) the person to contact when problems arise. Such a situation would probably facilitate this information being more readily available to the community-at-large and perhaps bring other children to the programme at an earlier age, thus partially alleviating the problem mentioned in the last paragraph.

The concerns of these parents in the Gaza Strip echo those of their counterparts in many areas of the world. What will happen to my child when he/she is too old for this programme? My child needs to attend school. What does the future hold? Will my son ever be employed? Will my daughter ever marry? Under the present conditions of poverty and oppression, it is amazing that an early intervention programme of this quality even exists. One can only hope that it will serve as an inspiration to those who seek to develop a comprehensive range of badly-needed services for the handicapped people of the Gaza Strip.

SUMMARY

In-depth interviews were conducted with 34 families who were participating in an infant development programme in the Gaza Strip. Results suggest that inter-marriage rather than maternal age was the prime reason for the children's handicaps. Families expressed great satisfaction with the programme possibly due more to the support they receive from the home teachers rather than the progress made by their children. Parents further decried the lack of follow-up services. Also included are recommendations to increase the visibility of the programme in the community so that parents will enrol their children at an earlier age.

ACKNOWLEDGEMENTS

The authors wish to acknowledge the invaluable assistance of the following Palestinian students who received their Diplomas in Rehabilitation Studies in July 1989:-

Mamdouh Abu Kamiel	Fuad El-Kordy	Kamal Jabr
Wael Dahab	Ghanem El-Miqati	Nasser Nofel
Marwan Diab	Mustafa El-Medalal	Mona Sakalla
Safwat Diab	Jamal El-Rozi	Izzedeen Zaqout
Hana El-Gergawi	Wael El-Wuihidi	Sabah Zeen El-Deen
Ala'a El-Hashem	Aida Hasseinen	Sahar El-Hayek

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